

Roundtable Discussion
Facilitator: Dr. Tuckson

DR. McCABE: Thank you very much.

Dr. Tuckson, I'll now turn it over to you as facilitator of the roundtable.

DR. TUCKSON: Thank you.

Well, we've got quite a robust amount of information. I guess as the moderator, I'll just ask -- I'll shock everybody. I'll just ask one question and then actually let some other people get in it.

I think, Joann, I really enjoyed your presentation earlier, where you sort of laid out a variety of roles that need to be played.

By the way, I want to keep in my mind always this constant theme we keep coming back to over and over again, which is what's different about this? What's new? What's special? How come this ain't just medicine and where is the delta between why this isn't just medicine or will be soon to this special little nugget, and what is that nugget and how do you define it?

But if you take the roles of family history and risk assessment and genetic counseling and information gathering and then there are diagnostic issues and risk assessment and then management and care coordination and supportive services -- I mean, there is this variety of things -- I guess I'm still struggling with how do we then decide who does what? How do you know who has the qualifications to do what? And therefore, as so much of the thesis of this, part of this, is that people keep saying they want the reimbursement to follow, you've got to have some idea then what is this service that people want reimbursed? Who's eligible for doing it? How are they accountable? So that when money is paid to people for doing things, you actually have some idea of what you're buying and some idea that the person that's doing it is qualified.

So I guess it's a large question all in one, but at the end of the day it's how do we decide who does what? What's the certification that folks ought to be able to have? Who makes those decisions? And then maybe we can start figuring out something about what it is that people get paid to do.

DR. BOUGHMAN: There was a question in there. (Laughter.)

DR. TUCKSON: Yes. How do we approach that? I mean, that's what I guess it boils down to is at the end of the day, how do we make progress in making these determinations? I guess I'll make the question easier. Are we getting there on answering these questions?

DR. BOUGHMAN: I think by necessity we are getting there, just as in any other field services or tests or diagnostic procedures, whatever it is, are in fact coded and reimbursed for the procedure. In the CPT codes, it doesn't say "as done by" and then say an oncologist had to order or perform this test or interpret a test. The code itself for the activity or the service doesn't include that process. So I think there are ways that we will get there by actions alone.

The question about who is competent, really, to do these things I think will depend on the definition of the service provided. The interpretation of a single carrier CF test is different, I believe, than doing the risk assessment and counseling an entire family. The coding process is going to have to be done in such a way that there would be differentiations, and I know that there is much discussion going into these kinds of things and separating out these issues in the level of

service.

DR. TUCKSON: One last little quick question. Robin, maybe you can help me then. Actually, that helps me a lot. Thank you, Joann.

The genetic counseling, then, at some level, there's a service called genetic counseling. Not everybody today in terms of reimbursement will pay for a genetic counselor unless it's ordered by a physician. If the counseling is ordered by a physician, then there is a genetic counselor who can then provide that service.

Should genetic counselors be able to provide this service of genetic counseling without a physician's order? Should they be able to generate their own demand today?

And secondly, should anybody else out there be able to do genetic counseling other than one of the people who graduated from one of these 25 accredited programs that therefore have some official standing as a genetic counselor?

MS. BENNETT: I think those are complicated questions because the billing and reimbursement issue is something that the National Society of Genetic Counselors is trying to address right now to figure out some of those issues about are we getting reimbursed now.

In general, the licensure bills so far have said that genetic counselors will work under the supervision of a physician. That doesn't mean that they can't order the testing, but that there is different oversight in terms of working with a physician.

I think that right now, given the complexity of the genetic testing, that it's good to have that relationship working with someone else. I think genetic counselors in general work as a team, although some are in private practice. Most of them are working with a physician, maybe in primary care or oncology, and recommending genetic testing that they're authorizing and then the genetic counselor is interpreting it, or they may be working with a medical geneticist.

DR. BOUGHMAN: Let me give you another example. Several years ago, there was a real challenge about molecular genetic testing, and the perception of the geneticists that there was an underlying amount of understanding of genetics that would be required to perform and interpret these tests correctly.

Pathologists, on the other hand, had the perception we've been doing complex tests for years and years. We can adapt and incorporate. We were head to head. In fact, the American Board of Pathology and the American Board of Medical Genetics were able to work out a one-year training process that a pathologist can go through and have certain specialized training and be equally certified to perform that level of complexity of tests.

Let me just throw out another example. We've heard that in nursing there are certain specialty certifications that are done, for example, in the oncological situation, oncological genetics, that in fact could or can be, if we so choose, integrated in such a way that there would be circumstances where everybody can agree if we work hard enough together.

DR. TUCKSON: Excellent answers. Debra, and then Hunt.

DR. LEONARD: In fact, I'm one of those pathologists that's now certified by ABMG and ABP in molecular genetic pathology.

A question. Can you clarify, Joann? You said that there are now medical genetics residency programs.

DR. BOUGHMAN: Yes.

DR. LEONARD: But there are 175 slots and only 78 are filled, and you made a statement that you can't fund the residency slots. I'm co-director of our residency program, so I understand. We have 35 slots and we can't expand that, come hell or high water. It's mandated by somebody and I don't know who.

So who would allow the medical genetics residency programs that are now new programs to create new slots at those locations for that residency program and can we do something to facilitate that process?

DR. BOUGHMAN: Actually, Dr. McCabe may be able to help us here, in his role as a chair, but some combination of the hospital and the medical school itself in designing residency programs, but because the money comes back to the hospital, I believe that is the place where the number of residency positions overall, the cumulative number across all specialties, is determined.

So in your 35 slots, if at your hospital a new program came up, you would have to give up one of your slots to medical genetics.

DR. LEONARD: So the number of slots per institution, per hospital, is set by CMS? Who sets that and can that be asked to be expanded for medical genetics, new medical genetics programs?

DR. McCABE: It's set by Medicare funding. So I assume therefore it's set by CMS. It's amount of dollars and that is linked to the number of residents there are, but it's also a complex formula that involves inpatient and outpatient experiences as well. Then you have to recognize we're not one of these, but as a pediatrician, I have to point out the freestanding children's hospitals until very recently did not receive the Medicare funding, and it's under threat again is my understanding. So the way we pay for trainees is quite arcane and it's a serious issue.

The other thing is that with these combined programs, my understanding is that it only pays for the first training, so that if you're taking three years to do pediatrics, but now you can do pediatrics and medical genetics in five years, the last two years are on the back of one of the departments in the medical school, not paid for by the hospital.

DR. LEONARD: So is there a way to change that?

DR. McCABE: My guess is that there are a lot of constituencies that want to change this arcane formula, and that this would be a relatively small constituency. Sure, one person can change the world. I don't know if this is a world that one person could change.

DR. WILLARD: Just to clarify a little bit, my understanding, at least as of a few years ago when I was playing that role, is that it's the dollars that are set, not the number of slots. So any hospital can add more slots. It just has to self-fund them. So you can add five more residents for anything the hospital decides is important to it, but it's going to have to find its own way of financing it, and some hospitals do that.

DR. LEONARD: Right, and in fact we have many more than 35 residents that we fund.

DR. WILLARD: Right, and some hospitals and programs do that and others, of course, don't, depending on their priorities and financial situations.

DR. LEONARD: Right.

DR. TUCKSON: Debra, do you have another question?

DR. LEONARD: No.

DR. TUCKSON: Hunt?

DR. WILLARD: Thank you.

Two questions for Robin. One, I wanted clarification on your assessment of cost because you referred to genetic counselors volunteering to teach and volunteering to train genetic counseling students. Are not most genetic counselors salaried at their institution or are they paid on a per visit basis like a barber?

MS. BENNETT: Many of the genetic counseling programs will have maybe one or two funded positions for training genetic counselors or they'll have a program director, maybe some medical geneticist's salary, but they bring in many other outside speakers who are genetic counselors, and I'm aware of very few -- any funding for the supervisors when they go to the clinical rotations.

So people are being paid to be a genetic counselor, but they're supervising students, which is taking more time. They're supervising their theses projects --

DR. WILLARD: But it's not hurting their take-home pay. It is simply a question, within that institution, to juggle whether enough patients are being seen and whether the division chief or the chairman of the clinical department or whatever it is feels he or she is getting enough bang for the buck in terms of the outlay that's going to pay three genetic counselors and one supervisor.

MS. BENNETT: Well, I think that it limits the number of placements. People aren't willing to take a student on because they're bearing the expense of educating that student and taking time to review cases with them.

DR. WILLARD: Right. Fair enough, but for this committee, it would focus, and least my thinking is, we're trying to identify what's a federal role here. What are the issues Secretary Thompson's going to care about? I would view that issue, as a former clinical chair of a clinical department, I would focus that attention on enlightening clinical chairs and to what degree they prioritize not only genetic counseling as a service, but also genetic counseling training as a training exercise for the development of new professionals.

So I see it less as a federal issue as I do an academic leadership and hospital leadership issue. But that's just my comment. I'm just one person.

The other question I wanted to get clarification on from the standpoint of the NSGC, and it was Reed's question but I didn't hear the answer, which was, again, what is the model? What's the vision here? That all genetic counseling should be done by a professional genetic counselor? And if the answer is yes there, then that's going to focus us on numbers of training programs and the workforce projections, et cetera.

Or is it going to be similar to what we discussed before lunch, where very complex issues, there needs to be professional genetic counselors, uppercase GC, to do that, but that all kinds of people, if we educate all kinds of health professionals well, all kinds of people can do lowercase GC?

Those to me are two very different models with two different long-term outcomes.

MS. BENNETT: I think that the National Society of Genetic Counselors feels that there's certain competency, that if you're going to call yourself a genetic counselor, that you should have. Some of that may be a credentialing process, but in general, if you're going to provide the counseling component with the genetics component that is necessary for many complicated tests, then that should be done by a genetic counselor or a medical geneticist.

DR. WILLARD: As a quick follow-up, that's going to be a long uphill battle, it strikes me, because just as we saw before lunch for all things genetic, I would think that there are all kinds of health care professionals who think that at some level they can do lowercase genetic counseling. You may want to give it another name, but that they can provide simple estimates of risk and interpretation of certain kinds of tests.

MS. BENNETT: I agree with you. I'm not disagreeing with that at all.

DR. TUCKSON: CDC, Tim. Timothy Baker, for the record.

DR. BAKER: Yes, as we were talking about health professionals -- you know, our favorite subject here -- looking at the continuum of health professionals as we train health care providers all the way through the various disciplines of public health, I want to remind the committee and the audience here of the variety of disciplines that need to continue to be engaged in the public health world, and we at CDC have been trying to marshal this notion of fitting genomic knowledge that comes from all sources -- and it's been mentioned, family history is certainly genomic knowledge, and much of the discussion we're having here -- in answering existing questions that we know there's variability and risk of fundamental epidemiology. They don't need a new science. This is helping answer existing questions within that science.

Then the notion of health education. How do you explain to families that they have differences in disease risk in common diseases? Well, we're all expecting that this is going to help answer some of those questions.

So I just I guess would bring to the attention of the discussants here that as we're looking at answering one of the questions I think that Dr. McCabe brought up earlier -- he was commenting on one of the reasons perhaps students don't go into medical genetics is because of this notion that you're pointing out a problem, rather than something that may be helpful or promising -- to some extent, the reason we named our office back in '96 the Office of Genomics and Disease Prevention was this notion of trying to tease out that knowledge and recognize when it fits into answering those questions about risk factors of disease, so we can target interventions effectively and bring it to the health of the public.

So at some juncture, we need to move more carefully into that, along with the discussions you're having here.

DR. TUCKSON: Terrific. Good comment. Thank you. Emily?

DR. WINN-DEEN: So I was struck when I read through the book there was a plea from the person who wants to start a genetic counseling program in the State of New Jersey for funding. You know, how can this committee help get funding?

I have to say, my immediate reaction is why isn't the State of New Jersey stepping up to the plate? I mean, the argument was the state needed counselors. Most people when they're trained tend to stay geographically near where they're trained for their jobs. Why are the state medical colleges not stepping up to the plate and creating training programs for genetic counselors and providing the diversity scholarships and all the other things that are needed to have the counseling community reflect the diversity of the community they would be serving?

DR. BOUGHMAN: Let me jump in and put a former hat of mine on as provost at one of those state universities, and we actually did get a genetic counseling program started.

It's simple economics. You have a situation where state medical schools, in many situations, are actually funded primarily from NIH research grants and clinical income, and the state portion of what goes into those budgets is relatively minimal. In the School of Medicine at the University of Maryland, only 12 percent of the School of Medicine budget was state dollars. Everything else was everywhere else.

Now, the individual states, you know that the budgetary constraints that we're having -- we've most recently heard about California -- bring down the size of the state and the number of millions or billions of dollars may be less, but the state budgets are going down, and with the NIH budget, unfortunately after years of going up, now being flat, the state medical schools especially are getting crunched from two directions. So the initiation of new programs while you are trying to maintain programs you have is an incredibly big challenge.

DR. WINN-DEEN: So having also lived in Maryland and watched the really good job that they did with creating undergraduate programs to graduate people with skills in biotechnology to meet the local employment needs of the biotech sector in Maryland -- I mean, if a state has a need for these professionals, I really think the state should step up to the plate and take care of their needs. You know, this was a half a million dollar start-up grant. This was not something that was billions and billions of dollars.

DR. TUCKSON: Thank you.

Ed, we'll come right to you in one second, but Robinsue was right before you. You're from the Office for Civil Rights.

DR. FROHBOESE: Right. Robinsue Frohboese with the Office for Civil Rights at HHS. I wanted to pick up a little bit on Emily's theme of diversity, but take a little bit of a different angle, and that is during the past two days we've heard this thread throughout of lack of racial and ethnic diversity across the board in terms of the population for research and testing, as well as when we get to the provider side in terms of clinical geneticists and lack of diversity.

Robin has touched a little bit upon the issue of providing scholarships, and one question that I had wanted to ask in the morning, and I don't know if Dr. Cooksey is still here, but perhaps -- oh, great. Good, because one thing that you talked about that I think might address this issue, because we've been hearing this identified as a challenge but really haven't heard about solutions, and you had mentioned a promising grant at the University of Texas that HRSA is funding that will deal with border populations between Texas and Mexico. I wonder, just from the brief

description that you gave, if this was a project that is going to get at some of the racial/ethnic diversity issues in terms of service population, research population, testing population.

DR. McCABE: We can have a brief comment.

I was in Texas for a while. The Rio Grande Valley is 85 percent Latino and underserved, critically underserved, and I know the services were being provided by the state with geneticists flying in, but there is a tremendous need in that community for services that will do more than just fly in geneticists, but will actually bring services to bear and provide role models for the young people in those communities.

MR. McINERNEY: If I may -- I'm sorry, Judy -- you might want to look at a program at the University of Cincinnati. Cindy Prowse, a nurse there, is running a program to educate nurses from minority and underserved communities and populations in genetics. I think that might be a nice model for this group to take a look at.

I think it's important to think not just about training genetics professionals from minority and underserved populations, but to think about how to reach underserved populations, whether you're reaching them with individuals who are themselves minorities or not. I think that's important.

DR. TUCKSON: Judith, did you want to make a quick one?

DR. COOKSEY: I believe it's a short, funded supplemental program that I think is looking at and trying to clarify some of the access issues and who is getting genetic services and who is providing it. There are many other efforts to try to improve diversity, but I don't think that one is specifically focused on improving diversity. I think they'd like to do that, but their focus is different than that.

DR. TUCKSON: Thanks for answering the question. Ed?

DR. McCABE: Yes, I just wanted to remind everybody, as we were assembling the group, that HRSA does consider training of genetics counselors as training of allied health professionals, and does have funds for those training programs, and so I think it's very important that we recognize that and that that be a source of funding for new programs as well as existing programs.

Having been a part of the program at the University of Colorado, these are incredibly personnel-intensive training programs, and that's part of the problem to a health center administration.

DR. TUCKSON: Ed wants us to break off, but Debra, you want to get one last comment quickly?

DR. LEONARD: Could somebody clarify, either Dr. Sullivan or Robin Bennett, is there a CPT4 code so you can bill for genetic counseling and what is the Medicare reimbursement for that? And then what gets reimbursed in other settings, you said you were looking into.

DR. SULLIVAN: I left my CPT code book back in Baltimore, so I don't know exactly the answer to that, but I can find that out. I am a certified professional coder. Also a CPCH.

DR. TUCKSON: But there is a code. If a physician orders it, there is a mechanism by which physicians' offices can tell payers what happened, that something happened called genetic

counseling. I just don't know what the reimbursement is.

DR. SULLIVAN: The answer is 28V, 28 Victor. And how much does that get you?

PARTICIPANT: It depends. It's time and hourly.

DR. TUCKSON: Time and hourly-dependent.

All right. Well, thank you. Let me just thank Joann, first of all, for your coordinating of both of these sessions today. We really owe you a debt of gratitude.

I think that Hunt raised an important focus that Ed picked up on, which is starting to try to drill to what can the Secretary do, and Ed sort of gave a very specific example of that in terms of HRSA and those resources.

I'm not sure how the rest of the committee feels, and we've got some time, I guess, where we're going to talk about what the next steps are, about whether or not we feel that, having been given this excellent foundation, now the question is what do we do with it?

I know, for one, that you've whetted my appetite for wanting to know a lot more about if we were to project five years from now, what is the work of the workforce for genetics? How does this get integrated into what a cardiologist, an oncologist, and so forth -- what do they do in five years? What will their work be? Therefore, what support will they require to be able to exercise their clinical practice?

Some of that support it sounds like from time to time may be a counselor. Some of that support may be an Internet site that provides a very real, functional, moment-by-moment set of supplementary information that a physician may need. I mean, there are a variety of supports that are going to be required.

I think one other thing I'm taking away from this is that I am left with some concern about how well the academic establishment in each of our disciplines are retooling the academic enterprise quickly to be able to meet some of these challenges. It sounds like a lot is going on. Everybody's kind of happy that things are moving. Whether or not those activities are adequate to meet the needs of the nation in five years, certainly it seems to me a big question mark, and I don't know what to do with that anxiety.

Thank you.

DR. McCABE: Thank you very much, Reed, for this session, and thank you to the speakers.

While you're stepping away from the table, Alyssa Johnson is from the National Council of State Legislatures, and so perhaps she can just briefly give us some insight into the state issues.

DR. FEETHAM: Before we move to that, I would just like to say that Dr. Joan Weiss from the Bureau of Health Professions is here, and from the Division of Allied Health, and those of you at a later point may want to approach her and talk about availability of TA, technical assistance, from Allied Health in regards to funding, resources, and applications, et cetera.

DR. McCABE: And Joan Weiss is sitting over here, so Robin, you can't see her when she stands up now, but perhaps you two can huddle at the end of this session.

So, Alyssa Johnson?

MS. JOHNSON: Thank you, Dr. McCabe.

I'm happy to offer any insight that I might have and answer any questions, but actually I have a question for Joann. I do work in the health care program at NCSL, and not education, so as a follow-up to the discussion on funding a genetic counseling program at the University of Maryland, I'm wondering, when those dollars were appropriated, if you used state funds, are they specifically given for, for example, a genetic counseling program or is that up to the university itself?

DR. BOUGHMAN: It was out of university funds, the state dollars that came to the university, and then allocation from below that level.

MS. JOHNSON: Okay. So it's not a legislature decision. Thank you.

DR. McCABE: Thank you.